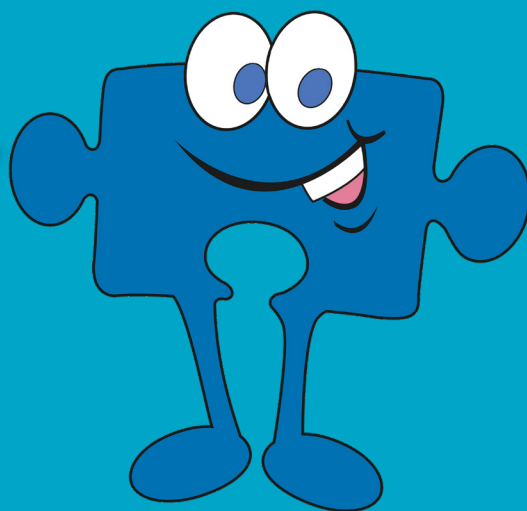




LHM KIDZ

I have a special heart
Your heart

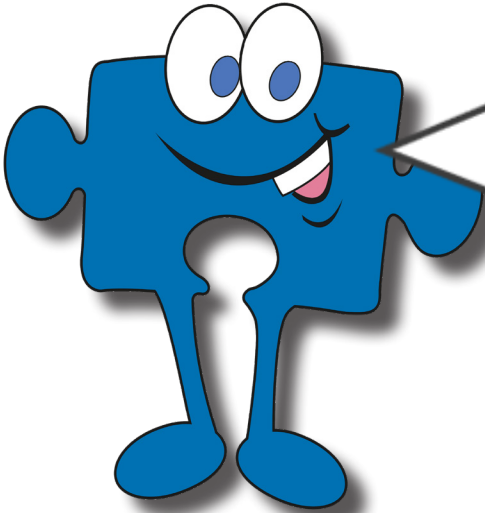
Let's discover
about your
special heart
together!



Specially created for our young members

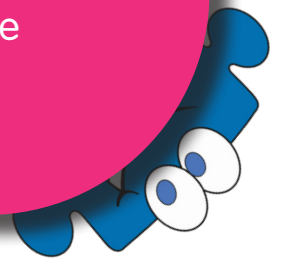


What is a special heart?

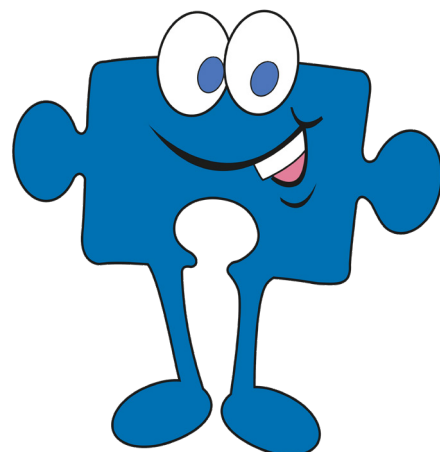


Some of our LHM kidz have a really good understanding of their hearts and what that means for their lifestyles, while some haven't really given it much thought. While it is completely fine to leave all the technical stuff to your parents for a while longer you may want to start discovering a bit more about your special heart, and that's where we can help!

Having a special heart means you were born with a heart condition. There are lots of different types but yours is called a single ventricle heart condition. Which means that part of your heart didn't grow the right way when you were a baby and you've had to have surgery to make your heart work better. But, having the surgery won't completely fix your heart.



I want YOU to take some time now to figure out what you KNOW and what you DON'T KNOW.





Let's play the
detective games!



TASK

Find two different coloured pens or pencils (you could go with red and blue to match our logo!) With one colour fill in the answers to what you do know, and then with the other fill in the gaps by asking your parents, carers or even doctors until you have ALL the information!

What is the name of my special heart condition?

What is the name of the hospital I go to for treatment?

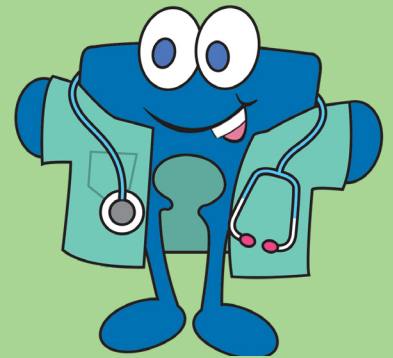
What is the name of my cardiologist (special heart doctor)?

What surgeries have I had?



How the heart works

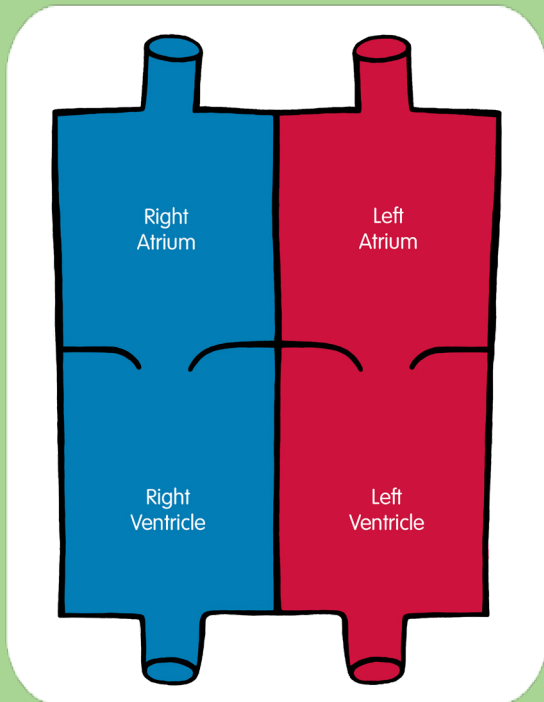
Understanding your heart and how it works is really important for everyone. When you have a heart that works differently from your friends, it becomes even more important to understand how blood gets pumped around your body. Before you can learn about your special heart you need to understand what the heart is there for. After every explanation, you will see words in brackets (). These words are the words that the doctors will use so read the simple and medical words so you can show them what you have learnt next time you go to see them. Here we go.....



Lots of people use a picture of a heart to express their love for someone. Heart emojis and hearts on clothes, Valentine's cards and heart-shaped balloons all show hearts in a simple way. We know that the heart, and the way it works, is a bit more complicated.

The heart's job is to collect and then pump blood.

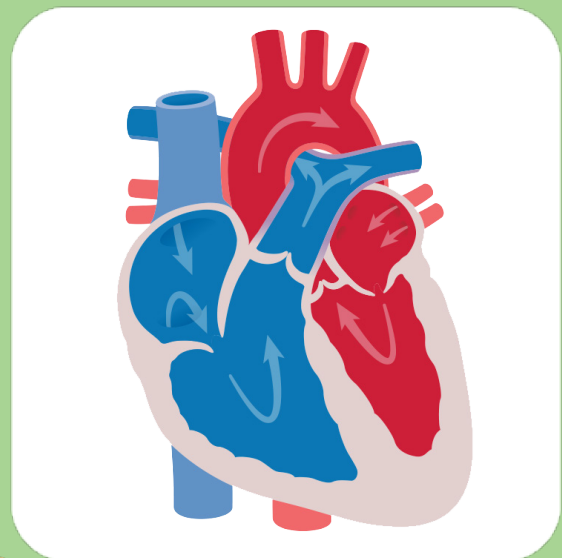
Blood, arteries and veins are a very important transport system, yes, a bit like roads. As blood journeys around your body, it picks up important things that you need to make energy. It then takes them to every part of your body. Smart! It collects oxygen from your lungs and food and drink from your gut. When your body has used up the bits it wants, it sends everything that is not needed to be breathed out from your lungs, peed out by your kidneys or destroyed in your liver.



OK back to the heart.

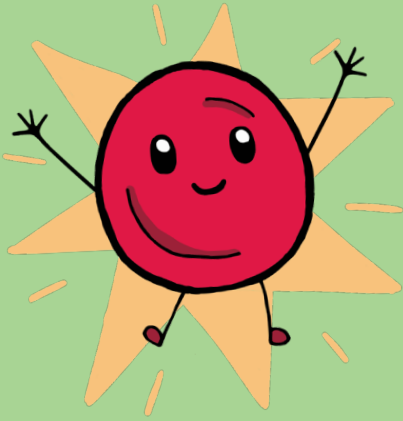
There are two sides to the heart. The right side, your right side, collects and then pumps blood to the lungs. Remember this is where the blood picks up oxygen.

Once the blood is as full of oxygen as possible it travels to the left side of the heart, which collects it and then pumps it round the body.



Did you know?
Oxygen-filled blood is **red**!
Blood with no oxygen has a **blue** colour.

OK, now we are going to take a journey through the heart. Look at the picture of the heart above and imagine you are a little red blood cell.



Hi George.
We are going to
join you on your
journey through
the heart.



George has joined up with his other friends in the blood. They are all travelling from the head and neck and body towards the right side of the heart.

They all whoosh into a collecting chamber (the doctor's name is the atrium). George can't rest though because suddenly the heart squeezes and pushes him, and his friends, through a door (in a heart this is called a valve) into a bigger chamber, the pumping chamber (the doctors' name is a ventricle). They know they won't be staying long. The heart squeezes really hard and they are all pushed through another door (valve) and on up into a big blood vessel (the Pulmonary Artery) into the lungs. George has lost his friends as they all whizz off in different directions but George can't worry about them because he has a job to do. He has to collect oxygen and get rid of gasses that he doesn't want in his body.

He can feel himself filling up, just like a car filling up with petrol. He is turning bright red and he feels full of new energy.

"Yippee," he shouts as he whizzes from the lungs down to the left side of the heart. He meets all his friends again in the collecting chamber at the top of the left side of the heart. He won't be there long, the heart squeezes and George and his friends are pushed through a door (heart valve) into a huge pumping chamber. It feels big and strong. Everyone says quick goodbye because they know that the heart is ready to squeeze and send us all up a big blood vessel (the Aorta) and then out of the heart.



The Aorta is like a motorway. It is the biggest blood vessel in the body and it leads George and his friends out of the heart and then sends them off down other big blood vessels to the brain, kidneys, and gut taking blood to every part of the body. Think of it as a road system, a motorway, big A roads, small B roads and then, by the time you reach the fingers, very small tracks.

George knows that all his oxygen will be used up as he travels because the body needs it to make energy. Gradually, as all the oxygen is used up, George begins to look a bit blue and he knows it is time for him to travel back to the heart and lungs to start the journey again.

Here's a link to a
video about how
the heart works.



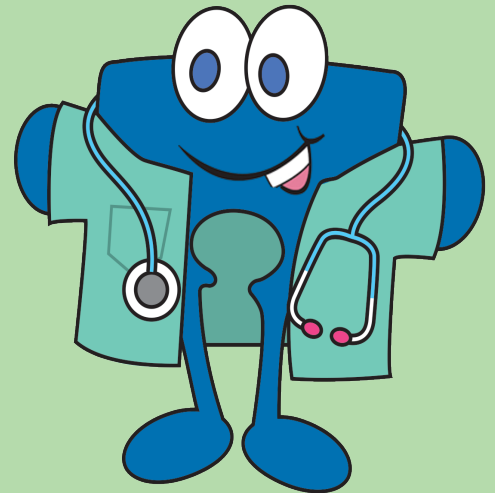
Here's a link to the LHM
animations which show
blood traveling through
a normal heart and how
it works for different
heart conditions.



Five main heart conditions

Do you want to know a bit more about your heart condition?

Tick the one that applies to you and compare it with our explanation about the normal heart!



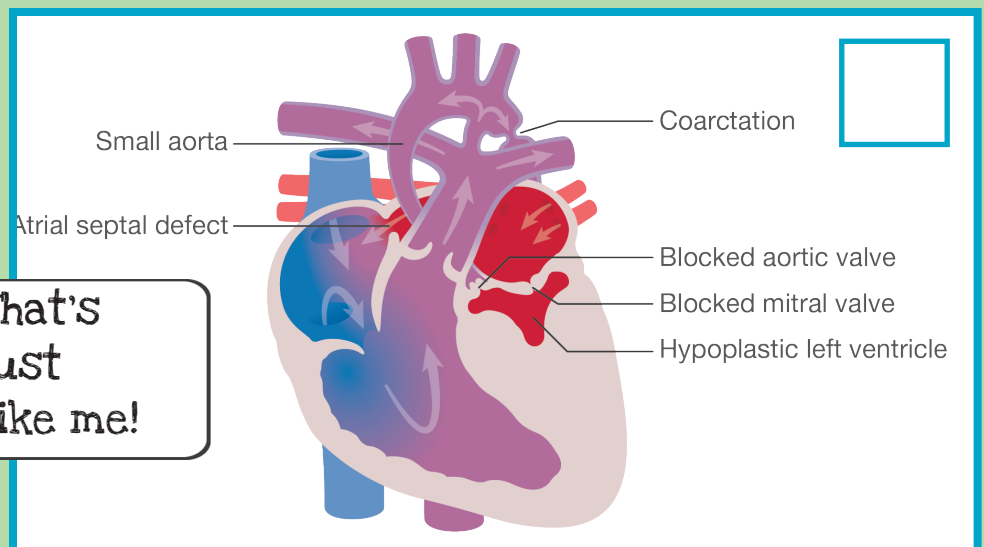
There are five main types of single ventricle hearts (half a working heart). Although the conditions are all slightly different, they have a lot that is the same. They have just one working heart pump (ventricle) not two and all of them need operations, and often medications, to help the heart work as well as possible and for blood to travel around your body.

Hypoplastic Left Heart Syndrome

Lots of our young members have this condition. All the differences in this heart are on the left side, your left side. This heart problem means that without surgery the heart can't pump oxygen-filled blood around the body. It means that George, the red blood cell, can't get the oxygen he carries through to every part of the body. Normally three operations help to reroute the blood and make the circulation of blood work better. Look at the left side of the heart to see the differences.

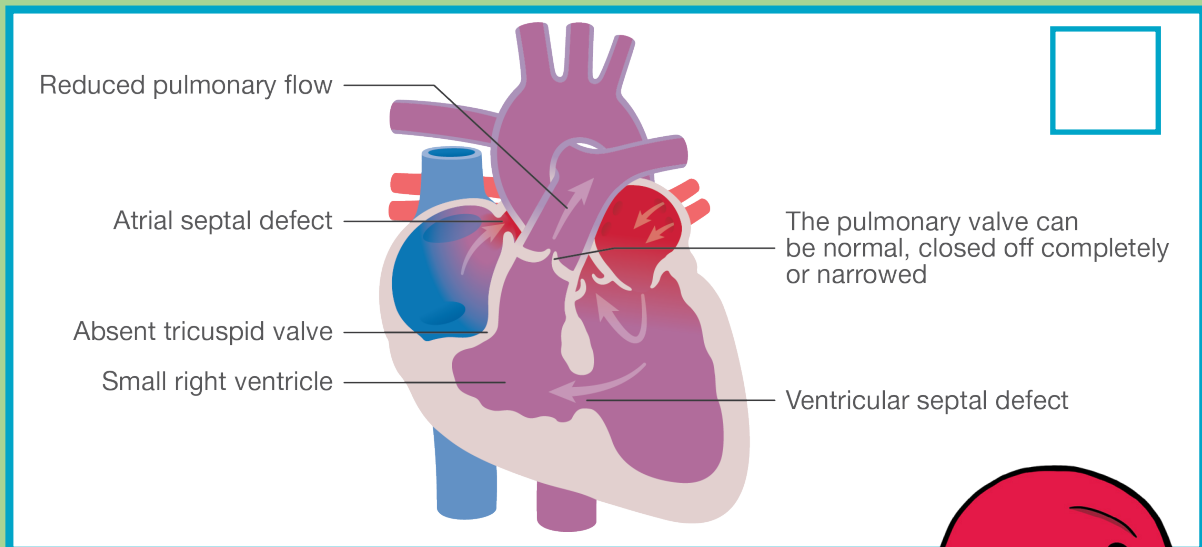


That's just like me!

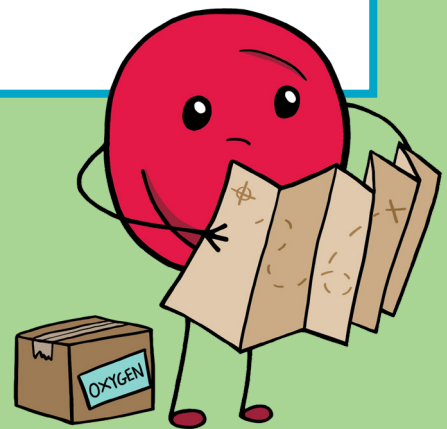


Tricuspid Atresia (TA)

Young LHM members with this condition have problems on the right side of their hearts. Having TA means that blood can't get to the lungs to pick up oxygen. George can't pick up the oxygen he needs to take around the body. Operations help to reroute the blood to the lungs and make the circulation work better. Have a look at the heart with TA and the normal heart to see the difference

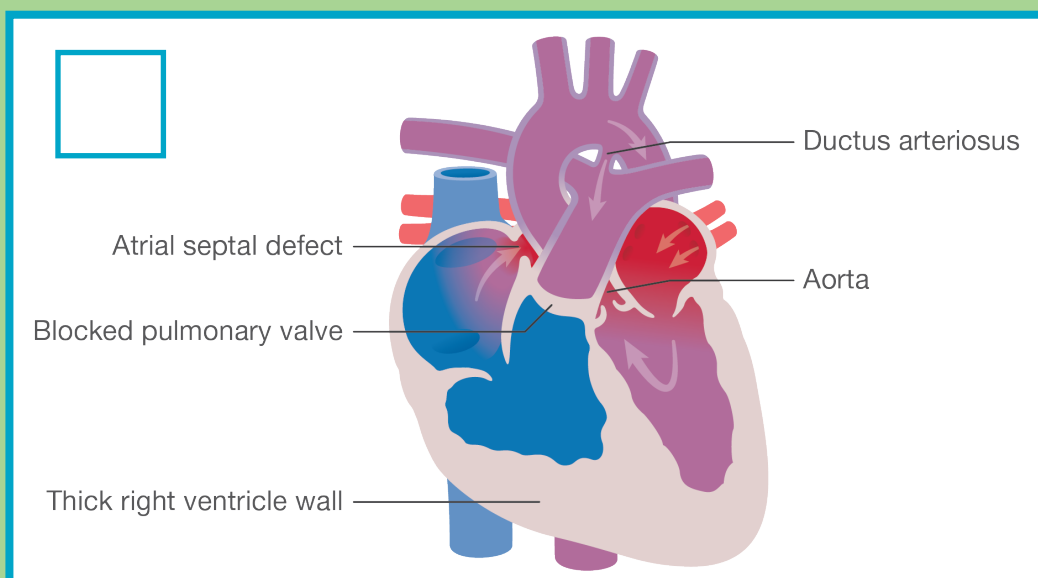


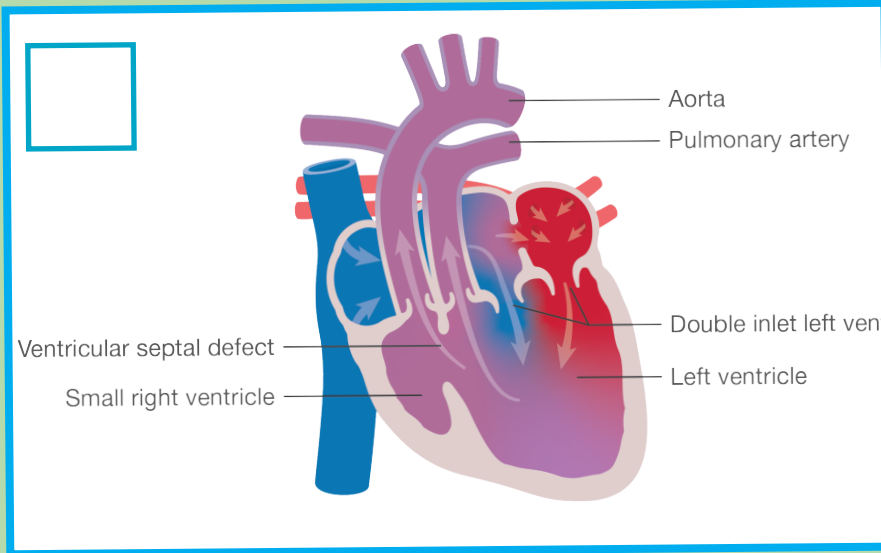
Sometimes it is difficult for me to find my way around the body to deliver oxygen.



Pulmonary Atresia with an Intact Ventricular Septum (PA)

Young members with PA have problems on the right side of their hearts. This heart condition means that George and his red blood cell friends have problems getting to the lungs to pick up oxygen to take around the body. Young people with PA have operations and medication to help get oxygen around the body.

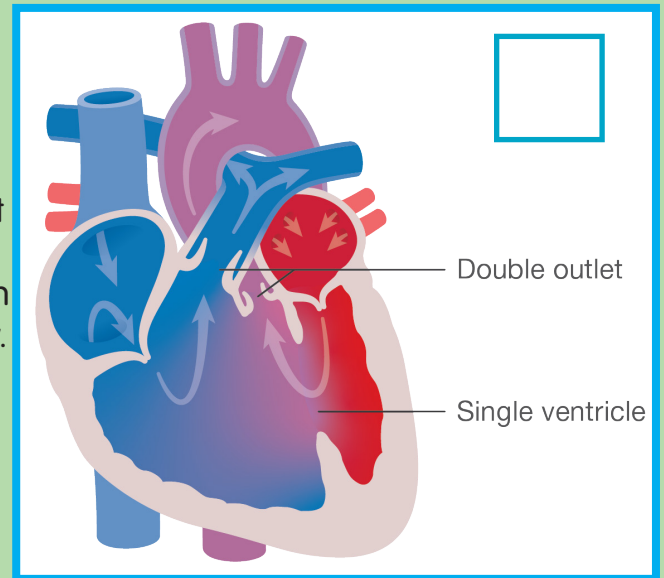




Double Inlet Left Ventricle (DILV)
 As you can see from the picture here this heart problem is in the middle of the heart. Blood goes in all directions but is not very organised and does not flow to the lungs very well. If you have this condition you will need to have a number of operations to help blood flow to the lungs so that George and his friends can pick up the oxygen they need to help you make energy.

Double Outlet Right Ventricle (DORV)

If you have DORV you have one big ventricle instead of two and blood travels from the heart in all directions. Everyone with this heart problem has a slightly different shape to their heart but doctors will do operations to make sure that blood can get to the lungs and that blood filled with oxygen can then travel to the body to make energy. George will be there to help carry the oxygen.



Other Single Ventricle Heart conditions

Not everyone has exactly the same heart problem and some of our young members do not have one of these conditions. They may have a very complicated Atrial Ventricular Septal Defect, or a condition called Epstein's Anomaly. Whatever heart condition you have the treatment will be similar to all the conditions above. The doctors will work to get blood to the lungs to pick up oxygen and then they will make sure that oxygen can travel to your body.



If you would like to see the films available about the heart conditions, scan the QR code!

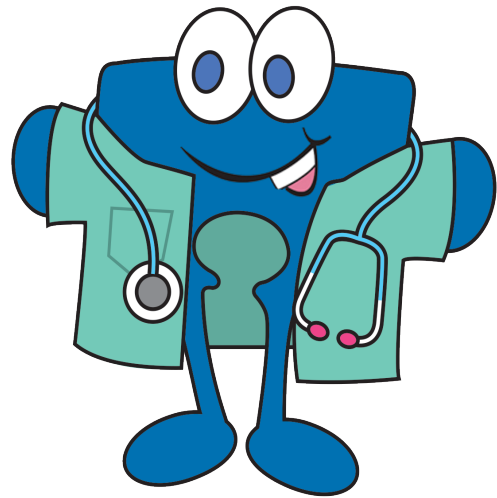


If I am worried or have a question who should I ask?

The doctor or nurse looking after you will always be able to help or give answers if you need them. If they aren't available, you can contact the team at LHM and we will help find the answers for you. email Olivia, your LHM Kidz lead at olivia@lhm.org.uk
Also, you can always have a chat on the LHM hub, some of our other members might be able to help.

Wow! Well done! You've learned LOADS about your special heart already!

If you feel like learning more check out some of the other LHM Kidz info packs we have available on your LHM Kidz webpage!

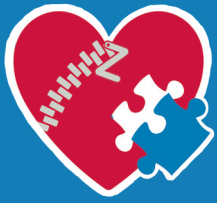


LHM Kidz info available:

- I have a special heart, what does that mean?
- My medication
- Hospitals do a lot of tests, what do they all do?

Jigzy is always working hard to bring you new information and content for your LHM Kidz webpage, so keep checking back to see what's new. If there is anything you would like to see in future please email olivia@lhm.org.uk to share your ideas!





LHM Kidz Youth Hub App



We have created a safe online space for all of our youth members living with half a heart. Here you can chat with Olivia, our youth mentors AND your LHM friends.

we have created three chat groups;

- LHM KIDZ - for our 7-11 year old members
- LHM JUNIORS - for our 12-14 year olds members
- LHM SENIORS - for our 15-17 year old members



You'll be able to access our online calendar and online youth groups to chat about life topics, or just chill and play games.

Just scan the QR code, create a profile and away you go!



Little Hearts Matter

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